Learning from Black Mothers of Persons with Disabilities: Reframing Policy and Practice During the Covid-19 Pandemic

American Academy of Developmental Medicine and Dentistry
Virtual Grand Rounds
Tuesday, August 4, 2020, 8pm
Ullanda Niel, 1 MD, CCFP and Nazilla Khanlou, 2 RN, PhD

1 Family Physician, Scarborough Centre for Healthy Communities, Willow Park School Clinic.
2 Women's Health Research Chair in Mental Health, Faculty of Health, Academic Lead, Meighen Wright Foundation Maternal Child Health Scholars Program, Associate Professor, School of Nursing, York University.

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Outline

1. Racialized Mothers study
   a) Background
   b) Challenges and strengths of mothers

Question Break

2. Practice and policy recommendations
   a) Recommendations for ‘approaches to care’ from 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities (IDD)
   b) Examining current stressors regarding race, disability and Covid-19
   c) Encouraging change within our workplaces

Question Break

3. Intersectionality-informed lens on impacts of COVID-19 on people with disabilities

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Conflicts of Interest

• None to report
Racialized Mothers Study

Principal Investigator: Nazilla Khanlou, York University

TEAM MEMBERS
Gail Jones - Neighbours Allied for Better Opportunities in Residential Support
Helen Gateri – MacEwan University
Deborah Davidson – York University
Masood Zangeneh – Humber College
Mahdieh Dastjerdi – York University

With Attia Khan, Luz Maria Vazquez & Tali Filler—York University

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What did we want to know?

What is an inclusive approach to health promotion for racialized mothers of children and youth with developmental disabilities?
Are you a Black Mother of a Child with a Developmental Disability?

We would like to invite you for an interview about your experiences raising a child with a developmental disability.

During the study interview we will discuss:

- The issues you face in raising a child with a developmental disability.
- How the issues impact your health and wellbeing.

Information shared during the interview will be confidential. As a token of appreciation for your participation, you will receive a $30 honorarium.

For further details, please contact:
Luz Maria Vazquez
Tel: 416-736-2100 Ext. 44527
Email: lvazquez@yorku.ca

Funded by Women’s Xchange at the Women’s College Hospital
The study has been approved by York University’s Research Ethics Board

Are you a Service Provider with experience serving black communities?

We you like to invite you for an interview about health promotion for black mothers of children with developmental disabilities.

During the study interview we will discuss:

- Challenges faced by black mothers of children with developmental disabilities.
- Types of health promotion strategies mothers recognize as inclusive and that have a positive impact on their health.

For further details, please contact:
Luz Maria Vazquez
Tel: 416-736-2100 Ext. 44527
Email: lvazquez@yorku.ca

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The study has been approved by York University’s Research Ethics Board
Challenges: No support from community, family or friends

“My support, I don’t know right now. I know there’s community support but personally, I’m withdrawn. My family’s not supportive, they don’t know how to be I guess... right now I’m not really doing much and I'm stressed out about finances” (P2).

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Strengths: Holistic approach to have a better society

“Exercising, good thoughts, good thinking habits, kindness, having love for people, regardless of how they feel about you” (P4).
Question Break

• In your opinion what are some of the strengths and challenges of mothers raising children with developmental disabilities?
Project Video
Mothering at the Margins:
Towards an equity-based health promotion framework for racialized mothers of children with developmental disabilities

The link to our video
https://nkhanlou.info.yorku.ca/
PRACTICE AND POLICY RECOMMENDATIONS
Mothers suggested:
Training/education/awareness for service providers about racism

“Service providers need to know that racism is embedded within a social structure within Canada and that racism limits people’s access to certain services and once they’re aware of this, they would be able to know how to advocate on behalf of racialized people” (P1).
Other emerging recommendations

- Service Providers with diverse backgrounds
- More information about services
- More Programming and services
- Hotline to support mothers
We would like to thank

The mothers and service providers who participated in our study,
Jahmeelah Gamble
and
Women’s College Hospital: The $15K Challenge
Primary Care of Adults with Intellectual and Developmental Disabilities. 2018 Consensus Guidelines.

- 2018 Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities (IDD)
  - Dr. William Sullivan, Surrey Place Center
  - Outlines standards of care to support clinical decision making including approaches to care, physical and mental health considerations.
- Available:
  - Canadian Family Physician Vol 64, April 2018
  - http://ddprimarycare.surreyplace.ca/guidelines/
A Person-Centred Approach to Care

- Engage patients and caregivers
- Identify a support person
- Provide sufficient time
- Discuss goals and values

A Person-Centred Approach to Care

• Engage patients and caregivers
  • Understanding your patient’s level of function
  • Tools for communication – visuals/videos/drawing pictures/ easy to read handouts
  • Office organizational tools
  • Today’s Visit

A Person-Centred Approach to Care

- Identify a support person
  - Supports pt autonomy
  - Attend healthcare appointments
  - Help to coordinate care
  - Monitor ongoing health and social needs

A Person-Centred Approach to Care

• Provide sufficient time

• Discuss goals and values


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Caring for mothers and other caregivers

• **Screen for caregiver needs**
  • Regularly screen for and proactively attend to the support needs of caregivers.
  • Recommend interventions that reduce behaviours that challenge in people with IDD (e.g. positive behaviour support)
  • Increase coping and reduce stress experienced by caregivers


Increasing coping/ reducing stress for mothers

- Mindfullness based stress reduction
- Patient/client driven groups/ seminars

Caring for mothers and other caregivers

- Monitor family or caregiver stress
  - When concerns arise, assess and monitor family or caregiver stress and advocate for respite or additional supports
    - Standardized inventories: Brief Family Distress Scale
    - Informal questions at visits: “How are things going?”

Stressors in my patient population

- Poverty (including working poverty)
- Employment at high risk of Covid-19 exposure
- Precarious housing
- Interaction with law enforcement
- Interaction with child protective services
- Need for education/support
- Neighbourhood safety
- Social connectedness/isolation
- Complex needs of new immigrants
  - Immigration challenges
  - Healthcare coverage (OHIP/IFH)
  - Language barrier
  - Core housing need
Disability and Race


Allison Norlian,
Forbes Magazine.
June 9, 2020
Covid-19 and Race

• The most ethno-culturally diverse neighbourhoods in Ontario, particularly in large urban areas, are experiencing **higher rates of COVID-19 and related deaths** compared to neighbourhoods that are less diverse.

• COVID-19 infections in the most diverse neighbourhoods **3x higher** than in less diverse neighbourhoods

• People living in the most diverse neighbourhoods were also more likely to experience **severe outcomes of COVID-19**
  • Hospitalization 4x higher
  • ICU admission 4x higher
  • Death rates 2x higher


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Covid-19 and Race

Covid-19 and Race

Share of COVID-19 cases among ethno-racial groups compared to the share of people living in Toronto, with valid data up to July 16, 2020 (N=3,861)

How can I encourage change within my workplace?

• Consider the **programming** offered by your agency
  • Do the materials used include Black people?
  • Do you celebrate or discuss important moments for Black Americans in your agency?
  • Do you offer culturally appropriate food options?
  • Do you have a diverse music selection for dance or fitness classes?

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How can I encourage change within my workplace?

• Create publications and resources that include the images of people of colour (social stories, pamphlets and handouts)

Socialstories4kids.com

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How can I encourage change within my workplace?

• Understand your patient population: consider collecting race/ethnicity based data to monitor for health inequities and to understand the impact of health outcomes, policies, programs and practices in on population subgroups.

Canadian Institute for Health Information. Race-Based Data Collection and Health Reporting. Ottawa, ON: CIHI; 2020.
How can I encourage change within my workplace?

• Include Black people and other marginalized groups in your research and quality improvement measures.

Niels & Khanlou (AADMD 2020)
How can I encourage change within my workplace?

• **Hire staff** that reflects the diversity of your patient population and provide an **inclusive culture** to support diverse staff members.


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Question

• What has your organization been doing well when combating systemic racism?

• How can you do better? What barriers do you anticipate?
Intersectionality-informed lens on impacts of COVID-19 on people with disabilities

• In the context of the COVID-19 pandemic, people with disabilities face increased risk of exposure, complications and death [UNICEF, n.d.].

• They also face accessibility barriers to prevention and response measures [UNICEF, n.d.].

• Limited data on people with disabilities results in the inability of surveillance systems to accurately determine the impact of current states such as the COVID-19 pandemic [UNICEF, n.d.].

Intersectionality-informed lens on impacts of COVID-19 on racialized people with disabilities

• Multiple intersections related to gender, race, ethnicity, socioeconomic status, sex, migration status and disability are shaping both the impacts of the pandemic on the population, as well as their resilient capacities.

• We know that people with disabilities have historically been socially and economically excluded. They face multiple social and economic barriers that negatively impact their health, mental health and wellbeing.

• A layer of complexity is added when we look at the experiences of racialized families with family members with developmental disabilities. The current pandemic is exacerbating health inequities among this population.
Ongoing projects
Funded by CIHR Project Grant
Knowledge Synthesis: COVID-19 in Mental Health & Substance Use
https://covid19mentalhealthresearch.ca/


**COVID-19 pandemic guidelines for mental health support of racialized women at risk of gender-based violence.**


**The impact of COVID-19 on the mental health and wellbeing of caregivers and families living with Autism.**
For further information about our projects please see our:
Website: https://nkhanlou.info.yorku.ca/
Email: owhchair@yorku.ca
Twitter: https://twitter.com/YorkUOWHC
https://twitter.com/NazillaKhanlou
Concluding Question

• In your opinion how can service providers support the wellbeing of Black mothers raising children with developmental disabilities during the COVID-19 pandemic?